

Autism Rate Now at One Percent of All US Children?

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A pair of federally funded studies on autism rates is about to make news -- big news -- and it isn't good: It would appear that somewhere around one percent of all US children currently have an autism spectrum disorder. The rate is even higher among six to 11 year olds and among boys, according to data from at least one of the new studies.

If you are an expectant parent, or planning to have a child soon, you might want to sit down before absorbing these staggering statistics, recently released by the [National Survey of Children's Health](#) (NSCH), which is supported by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services.

According to data from the 2007 telephone survey of parents of nearly 82,000 US children, the odds of a child receiving an ASD diagnosis are one in 63. If it is a boy, the chances climb to a science fiction-like level of *one in 38, or 2.6% of all male children in America*.

But there was also some surprisingly good news. Enormous numbers of children originally diagnosed with ASD went on to shed their diagnosis as they got older, parents reported.

Among all children aged two to 17, according to respondents, one in 100 (100-per-10,000) currently have an ASD diagnosis, which is considerably higher than the previously (CDC) estimated rate of 1-in-150, (or 66-per-10,000).

But researchers were also told by parents that 60-per-10,000 children "had autism, Asperger's Disorder etc. at some point, but not currently."

This suggests two rather remarkable things:

1. At some point in their lives, 1-in-63 US children (160-per-10,000) will have an ASD diagnosis and;
2. Out of every 160 children diagnosed with ASD, 60 of them (37.5%) will somehow go on to lose that diagnosis.

Among boys, for every 260-per-10,000 male children originally diagnosed with ASD, 90 of them (34.6%) reportedly do not have the diagnosis now. This still leaves a monumentally high rate of one in 58 boys with ASD today, or 1.7 percent (170-per-10,000).

The percentage of girls who apparently lost their original diagnosis was 44.5%.

There was a big difference among age groups as well. Among those children who still have the diagnosis, the rate of ASD was 40% higher in 6-11 year olds (140-per-10,000, or 1-in-71) than the current rate of 12-17 year olds (100-per-10,000, or 1-in-100).

Interestingly, among the youngest children, two to five years old, the rate was only half that of their six- to 11-year-old siblings, (70-per-10,000 vs.140-per-10,000). Most or all of that may be due to the average age of diagnosis, which is below five years, though it does bear watching to see if these younger kids go on to double their rates and "catch up" with the older ones.

Overall, the 2007 NSCH survey revealed a 100% increase in parent-reported ASD rates compared to the [2003 NSCH survey](#) (which showed a 50-per-10,000 reported rate).

The survey was conducted by the Data Resource Center of the Child and Adolescent Health Measurement Initiative (CAHMI) at the Oregon Health & Science University. And though the survey used what is considered to be sound methodology for estimating ASD percentages, most observers are still anxiously awaiting the release of more and even more reliable statistics -- expected soon from the CDC.

This second autism study, culled from data in the CDC's [Autism and Developmental Disabilities Monitoring network](#) (ADDM), has been eagerly anticipated for quite some time.

ADDM researchers examine the education and (when possible) medical records of all eight-year-old children in selected US cities and states. They look only at eight-year-old cohorts to allow time for all diagnoses to be made, reported and counted.

So far, ADDM has published data from just two birth cohorts: children born in 1992 (eight-year-olds in 2000) and those born in 1994 (eight-year-olds in 2002). The 1992 cohort revealed an estimated ASD rate of one in 166, or 60-per-10,000.

For the 1994 cohort, the estimate was revised upward to one in 150, or 10% higher, at 66-per-10,000.

CDC officials have been analyzing the 1996 birth cohort (2004 data on 8-year-olds) for years. I asked the agency a few months ago about the slow progress in releasing the numbers and was told that the data were currently "under review." No response was given to written questions about data collected from the 1998 or 2000 cohorts (in 2006 and 2008, respectively).

I also submitted a Freedom of Information Act request to the CDC for the raw data it had collected to date. That request is still pending.

But just the other day, the [Adventures in Autism](#) blog reported that CDC was about to release its 1996 birth cohort data, and that those data would also show ASD prevalence rates along the lines of 100-per-10,000, or a whopping one percent of US children.

The blogger, Ginger Taylor, reported that the CDC's new one in 100 figure had been mentioned at a recent national meeting of the Autism Society of America. So I called ASA President and CEO Lee Grossman to ask him about it.

It was Grossman himself who brought up the new studies, while introducing the keynote panel at the ASA meeting in St Charles, IL the week of July 20.

"I told people we were about to get hit by two separate studies that will be published in the near future," he said. The National Survey of Children's Health data will be published in September and the CDC's 1996 birth cohort data will also appear in print -- in the *Morbidity and Mortality Weekly Report* -- "probably before the end of summer, although that is not yet official," he told me.

Grossman said his sources were "good people" that he trusts, working within the CDC's ADDM network, which he termed the "gold standard" of US autism epidemiology.

According to his sources, the 1996 birth cohort will reveal ASD prevalence rates that are "consistent with other national large-scale study figures, and I assume that includes a study from the UK," Grossman said. That study put the UK rate at 1-in-83.

The CDC researchers also told Grossman that there were "some similarities" to what was found in the NSCH survey, even though NSCH and ADDM are "two extremely different instruments."

Assuming that the new CDC figures show a significant increase in diagnoses between the 1994 and 1996 cohorts, the overarching question, of course, will be, "why?"

"Did the numbers really go up, or is it better data collection? I don't know the answer," Grossman told me. "Are we monitoring it better and finding more kids? I suspect we are, though it is hard to say." He added that ASA was working with a few school districts that provide statistics on ASD rates, "and their numbers are closing in on one in 100 as well."

One possible explanation for at least some of the increase is that ADDM researchers became more proficient at obtaining the necessary records across their analyses of the 1992, 1994 and 1996 birth cohorts. For example, in the 1994 cohort, the ASD rate in New Jersey (where access to both medical and school records was possible) was 93-per-10,000, while in Alabama (where access to school records was not available) the rate was about one-third of that, at just 33-per-10,000.

Is it possible that CDC researchers somehow gained access to school records for, say, Alabama children born in 1996 that they did not have for kids born there in 1994, thus driving up the numbers? Of course it is, though we must wait for the published report to find out.

Another plausible explanation for some, if not all of the increase, is the expansion of the ASD classification within the public schools to include not only full-blown autism, but also milder forms of ASD such as Pervasive Developmental Disorder -- Not Otherwise Specified (PDD-NOS) and Asperger's Syndrome.

This has long been the argument of those who do not believe that the real number of ASD cases has increased -- they insist that the rise is simply an artifact of wider diagnostic criteria, greater awareness and/or more ASD services on offer.

I am certain that the expansion of ASD criteria in the early 1990's contributed to the increase in reported diagnoses during that time, though I am not personally convinced that this can account for the entire growth of cases.

And I do not believe that autism rates have always been one in 100, or one in 71, as currently reported by parents of six- to 11-year-olds in the NCHS study.

So, what else could help explain at least part of the ASD increase? I believe that environmental factors are at play. And rising levels of toxic exposures among pregnant women, unborn children and young infants must be fully examined.

Which leads us to vaccines: Could they be responsible, at least in part, for contributing to the rising ASD numbers?

"A person with an autism spectrum disorder has a number of underlying and seemingly unnoticed immunological, inflammatory or mitochondrial issues happening, and there could be any number of factors that trigger this," Lee Grossman told me, reflecting a growing consensus among autism groups and researchers. "And it is certainly plausible that vaccines are one of those triggers."

The whole debate over why the numbers are going up, Grossman added, "is sad." He lamented the fact that "people are trying to limit the debate and the science. But until we know what is going on, we should treat everything as a plausible factor, and study it to the point where we have a much better understanding. For example, why do some people have a severe reaction to vaccines and why do some not have that reaction? To me, it is appalling that those studies have not happened."

If there is an environmental component to autism, hopefully scientists will want to know which exposures might have increased between, say, 1992 and 1996.

One possible answer is the Hepatitis B vaccine, (which also contained 25 micrograms of mercury containing thimerosal).

Introduced in 1991, it was the first vaccine ever given on a population basis to newborn babies (within the first three hours after delivery) in human history.

But according to the CDC's [National Immunization Survey](#) (which also includes parental telephone interviews), only 8% of infant children received the Hep B vaccine in 1992, when that birth cohort showed an ASD rate of 60-per-10,000.

By 1994, the number of children receiving Hep B vaccine had reached just 27% -- and the cohort showed an ASD rate of 66-per-10,000.

But the Hep B coverage rate had risen to 82% by 1996, when that cohort's ASD rate exploded to around 100-per-10,000.

Correlation, obviously, does not equal causation. And no one is suggesting that Hepatitis B vaccine is the singular "cause" of autism. But the uptake rate of that particular immunization is at least one environmental factor that did demonstrably change during the period in question.

In addition, some recent studies and [Vaccine Court decisions](#) have supported the contention that Hepatitis B vaccine can damage myelin -- the nervous system's main insulating component -- at least in certain genetically susceptible adults and infants.

A [study published last October](#) in the journal *Neurology* found that children who received the Hepatitis B vaccine series were 50% more likely to develop "central nervous system inflammatory demyelination" than children who did not receive the vaccine.

Most of this increase was due to the Engerix B brand of the vaccine, manufactured by the UK's GlaxoSmithKline. That brand increased the risk of demyelination by 74%, and patients with confirmed multiple sclerosis were nearly three times more likely to develop the disorder.

"Hepatitis B vaccination does not generally increase the risk of CNS inflammatory demyelination in childhood," the authors concluded. "However, the Engerix B vaccine appears to increase this risk, particularly for confirmed multiple sclerosis, in the longer term. Our results require confirmation in future studies."

In another Vaccine Court Case, *Banks v HHS*, the Special Master ruled that a young boy named Bailey Banks suffered from a similar demyelinating disease called "acute disseminated encephalomyelitis (ADEM) following the measles, mumps, rubella vaccine, which "led inexorably" to his development of PDD-NOS, an autism spectrum disorder.

In Bailey's case, the myelin repaired itself, but the CNS damage was permanent. Most children with ASD do not show current signs of myelin damage, though many of them test positive for antibodies to myelin basic protein, suggesting that demyelination may have played a role at one point, as it did in the Bailey Banks case.

Another item that will surely spark fiery debate is the reason why so many previously diagnosed children with ASD are currently not holding that diagnosis.

There are three main possible explanations:

- 1) Many children never had an ASD to begin with, and were simply "misdiagnosed."
- 2) Some children naturally "recovered" from ASD on their own without treatment, (though Lee Grossman and many others told me they have never seen this happen).
- 3) Interventions including behavioral therapy, dietary changes and biomedical treatments actually work, and it is possible to recover a child from the grips of ASD.

One thing is certain however: No matter what the explanations for the increase -- and for the extraordinary "recovery" rate of children diagnosed with ASD -- the current US ASD level is still somewhere around 1% -- and 1.4% (140-per-10,000) among kids aged six to 11, if the NCHS study is to be believed.

Let's assume that the 140-per-10,000 rate is the most accurate: This would make the "autism is genetic and has always been with us at these levels" crowd appear to be pathetic, if not downright laughable.

Why? Because reputable studies from the 1980s showed that the actual rate of autism was about two per 10,000 children, not 140 per 10,000. If those studies were wrong, and if the rate was the same then as it is now (as many scientists contend), that would mean that doctors, educators and statisticians are now 7,000 percent more proficient at diagnosing and counting autism than they were before.

According to this logic, out of every 140 children who had an ASD in the 1980s, 138 of them went (and continue to go) undiagnosed, uncounted and untreated by medical and educational professionals.

If I were a medical or public health professional, that is a fact that I would not be keen on broadcasting.

And if the actual rate of autism in America is truly 1% - or 1.4% - then as ASA's Grossman said: "People ain't seen nothing yet."

"Everyone is going to cover this story, and the reality is that nobody is doing anything about the increase in autism," Grossman commented. "But when you get to a figure of 1% of the population, hopefully you'll get attention, and have people begin to act to help those with autism today with funding of services and support, and to get a better handle on how to spend research money."

Grossman said it was "terrible" that research into the causes of autism has been so heavily weighted towards genetics, at the expense of studying environmental factors.

"But now, many people believe that autism is associated with environmental triggers," he told me. "And my message is: 'Wake up.' But if this doesn't wake people up, then I don't know what will."

I, for one, concur with Lee Grossman.

"I'm hopeful that this unfortunate statistic, and the terrible growth in autism, will finally get people to act to do something about autism," he said. "And by that, I mean the fine folks in government who are not responding in the ways that they should."